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ABSTRACT

No theories of communication can minimize the crisis of dying. But those who study communication can suggest ways of offering comfort and dignity to the dying person. Many of these ways go beyond words, for death cannot be addressed with verbal cliches. The theoretical work from which a communication scholar draws can help hospice volunteers and personnel continue to find and value alternative forms of expression. Although honesty about death is essential to the hospice concept, such openness confronts long standing cultural and medical constraints. The personnel who serve the patient and family can in turn be served by the body of communication research and insight that supports the hospice commitment to honesty. Other information that a communication scholar might offer includes ideas on self-disclosure, particularly references to personalized nursing care; the role of communication in family crises, including their emphasis that honest expression is essential to allow healthy preparatory grief; and an awareness of the nonverbal signals that are often more truthful than words. As the treatment for a dying person moves from cure to comfort, the interaction with that person should move from therapeutic to relational communication. The communication specialist can support this recognition of mutuality by offering insights on helping relationships. Thus, the efforts of a caring team can be strengthened through self-understanding and objective confirmation of tested insights into communication. (HOD)

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COMMUNICATION ASPECTS OF HOSPICE CARE

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Abstract

Communication is central to hospice care for the terminally ill. As a team member or consultant, a communication teacher/researcher can offer insights which confirm and extend the hospice approach.

Communication Aspects of Hospice Care

From Dante's Inferno comes this line: "In the middle of the journey of our life I came to myself in a dark wood where the straight way was lost." Wherever we are in our own journeys through life, each of us knows the fear that darkness could fall in the form of illness and death. But perhaps death does not frighten us so much as losing our way in the face of it, of ending the journey in meaningless pain without identity and integrity.

Out of respect for the journey of life and the darkness which threatens it has come the concept of hospice. The term "hospice" derives from the way stations which were established for pilgrims to the holy land in the middle ages. Hospices provided places to rest and friends who honored the importance of the traveler's journey. Thus the pilgrim could complete the journey without straying from the way or becoming lost in Dante's dark wood. When Dr. Cicely Saunders founded St. Christopher's Hospice in London in 1967, she renewed the medieval concept of hospice and added the name of the travelers' saint. St. Christopher's Hospice was created as a way station for the dying, in the belief that every step of the journey is important and should not be darkened by pain, loneliness, and loss of selfhood.

The first fully operational American hospice was established in New Haven, Connecticut, in 1974 and has now been joined by approximately

500 developing hospices throughout the country--a remarkable growth culminating in official inclusion in the medicare system beginning in December 1983. In contrast to St. Christopher's, St. Joseph's, and St. Luke's Hospices in England (which are specialized independent facilities for the terminally ill), hospice services in this country are most often provided in the patient's home with wings of some hospitals designated as auxiliary hospice units. But these physical differences serve to underscore that "hospice" is not a place but a philosophy. Regardless of outer form, all of these way stations offer care when there is no cure--and all uphold the dignity of the journey. Because this concept is not limited to a physical place, we may appropriately speak of "hospice" instead of "a hospice."

Central to the concept of hospice care is recognition of several kinds of pain: emotional, psychological, social, spiritual, as well as physical. To address pain in all its forms, hospice care is provided by teams which include physicians, nurses, social workers, religious counselors, and trained volunteers. The concept of an interdependent team was recognized in the New Haven model and continues as a basic precept. One of the founders of the New Haven Hospice wrote during its planning stage: "To carry out the above program means . . . a dedicated and competent staff that will not be afraid of knowing each other, supporting each other, and blurring roles so that there can be a shared effort rather than jealously guarded 'turf' by any professional group" (Dobihal, 1974, p. 367).

Because communication is essential to the complex relationships of the hospice team, family, and patient--this paper will suggest some ways

that communication scholars can contribute to the hospice effort, as professionals with some insight into psychological and social pain. The communication specialist, like everyone else involved in hospice care, must first be willing to accept a role which is blurred, adapted, and submerged into a larger team effort. The initial involvement of a communication teacher/researcher might be as a patient care volunteer, a hospice board member, an instructor in volunteer training programs, or a consultant to the professional staff and volunteers. But regardless of the particular role, the communication specialist can offer valuable knowledge derived from communication studies. These contributions include: (1) recognition that communication extends beyond words, (2) affirmation that helping relationships demand honesty, and (3) insistence that communication, even in extremity, must be reciprocal.

Communication Beyond Words

No theories of communication can minimize the crisis of dying. But those who study communication can suggest ways of offering comfort and dignity to the dying person. Many of those ways go beyond words, for death cannot be addressed with verbal clichés. The friend of a dying woman offers this reminder of the limits of words:

> When Eleanor opened her eyes for a moment and saw me sitting by the bed, she reached toward me. "I'm afraid," she whispered. I didn't know how to respond, so as soon as the day nurse came in, I asked her advice. "You'd better ask the doctor," the day nurse said. The doctor didn't come, so I went to the night nurse when she arrived. "What <u>can</u> you say?"

> the night nurse murmured, patting my arm. "You should call the chaplain. Let him reassure her." Eleanor did not believe in churches or chaplains, so I asked the resident when he came by on his rounds. "You have to give her some supportive psychotherapy," he said. "Just tell her there's nothing to be afraid of." I didn't agree, and when her doctor appeared, I asked him. He looked troubled and a little embarrassed. "Tell her . . . tell her she's apprehensive." A little student nurse looked in at the door, a beautiful blue-eyed child in a starched pinafore, and, cruelly, I asked her: "What should I say when she tells me she's afraid?" The little nurse bent her head quickly and stared at the tips of her shoes. "Aw gee," she said softly. She raised her head and looked at me, her eyes gleaming with tears. "Aw gee," she said again. Here, at last, was an answer I could understand. (Barthel, 1972, p. 55)

Susanne Langer (1951) wrote of finding the right symbolic form in each particular instance to convey the intended thought or feeling. These symbolic possibilities always include much more than words, but the intensity of terminal illness and the inadequacy or loss of verbal abilities make urgent the search for alternative forms of communication.

In recognition of this, a hospice social worker may encourage a child to draw a picture for his dying mother, while his father prepares the gelatin that she can still swallow and rubs her hands with scented cream (Lake, 1982, p. 63). Such communication not only reaches a patient,

but allows a family to feel less helpless at the moment and less guilty later.

The hospice approach recognizes that professional staff and families can complement each other in finding new ways of communication and sustaining intimate bonds. Craven and Wald (1975) write of this combined effort:

> It is important that caregivers discover the work a family can do that staff members cannot do, work which is rightfully theirs and that they can do best. For example, patients facing the close of life often use symbolic language. The nurse may recognize that the patient's apparently meaningless words, "Under the tree," "It's too small," "There will be four of us," are oblique references, but only a family or friend can provide the missing key: "The family cemetery plot bought long ago is under a tree, and there is only space for two graves." The nurse, now provided with that information, can, in turn, support the family and patient in discussing the painful yet necessary matter of funeral arrangements.
>
> A nurse's hand, though full of skill, is not the same as the hand of a loved one to mop a brow, rub a back, or touch an arm. A family's active participation in care is also part of the separation process itself, which includes giving and receiving, coming together, and letting go. Our clinical observations that family members who are involved

> in care are less prone to guilt and self-criticism substantiate the work of others who have compared the mourning process of widows who cared for spouses with widows who did not. (p. 1820)

Saunders (1981) describes the awareness that St. Christopher's Hospice shows toward the sensory experiences of a patient, and suggests that these vital senses provide a way to offer comfort. She writes:

> Over the years of caring for the dying we have learned that, although thirst may be the last craving, there are many more acceptable ways of easing it than intravenous drips; many flavors, including whiskey, may be added to ice cubes. Hearing and touch are the last senses to go. When death is imminent.. . . the patient . . . may still be hearing . . . [the family] and be somehow aware of their presence. I am sometimes asked: "Is it really worthwhile my being here? Does he know I am here?" To me, the answer is an analogy to a married person who doesn't sleep as well when the partner is away. He, or she, will not be awake all night, but something in the sleep is more comfortable when the other person is there. (p. 107)

In addition to the intrapersonal and interpersonal communication that hospice sustains through its recognition of sensory and nonverbal factors, the physical space in which the patient lives i carefully considered. The philosophy of all hospices, including the specialized care centers in Britain, is that a patient should remain in his/her own

home as long as possible. The self-control and self-identity which are possible in one's own home cannot be duplicated even in the best of institutions, and leaving one's own place is an additional kind of pain. Thus, a large number of hospice patients remain at home until death--with all hospice services brought to them.

However, when patients do need to leave their homes, the hospice environment is usually vastly different from a hospital. The designer of the New Haven Hospice speaks of an "architecture of healing" (Kron, 1976, p. 47), which he emphasizes is much different from a design for curing. Hospice designs often include maximum natural lighting, fireplaces, wood-paneled ceilings, lounge and patio areas, small gardens, chapels, common entrances for patients, staff, and families--and sometimes built-in day care centers for children of the staff "permitting children to see the elderly patients and the patients to see children, reminders that neither group exists in a world without the other" (Goldberger, 1980, p. C20). The District of Columbia Hospice is not unusual in its brightly colored furniture, coffee pots steaming in kitchenettes, and large picture windows. Saunders believes beauty is healing; being able to look out on trees "makes patients see that the creation to which they belong is good--it can be trusted" (Kron, 1976, p. 49). Even a converted hospital wing, as used by Cedar Valley Hospice in Iowa, can be substantially altered by painting the walls in light colors, installing fresh draperies different in every room, and using table lamps instead of overhead lighting.

Regardless of the physical setting provided, patients are allowed to fill their spaces with personal possessions (rocking chairs, photographs, books, antiques, quilts, throw rugs--even pets). Thus, the rooms in a

hospice are filled with the objects that express and sustain the resident in contrast to hospital rooms that store objects for use by the medical staff. In settings such as this, the deputy medical director of St. Christopher's says that visitors sometimes walk around for a time and then ask: "When are we going to see the dying patients?" His answer: "You've seen them" (Goldman, 1976).

The theoretical work from which a communication scholar draws can help hospice volunteers and personnel continue to find and value the alternative forms of expression. Langer's analysis of symbols and rituals has been followed by a growing body of communication theory. Montagu's (1978) analysis of the life-long need for touch is particularly relevant, for only touch can reassure a dying person that he/she is still attractive to family and friends. Buber's (1966) philosophy of dialogue emphasizes the value of shared silence and he speaks of ultimate communication as a "wordless being-with-one-another" (p. 94). Sometimes a communication consultant could use a case study approach, including reference to literature. This approach (Jensen, in press) might well include reference to Barton's (1978) novel A Reckoning, written from the point of view of a dying woman whose friends and family speak to her through flowers, champagne, and quiet music. A consultant could also draw from studies by environmental psychologists and offer insights from Sommer's (1969) work in proxemics and Burgoon and Saine's (1978, pp. 104-115) analysis of personal artifacts. These theoretical works offer no easy answers, but they do recognize the complexity of life and offer ways beyond words to honor life to the end.

Relationships Grounded in Honesty

In the euphemistic jargon of some hospitals, death has become "a negative patient outcome." Some doctors consider terminal illness a sign of medical failure (Goldman, 1976). Some dying patients avoid mentioning death to their doctors lest the physician be disappointed or depressed (Wessel, 1975, p. 18). Some families also join in the denial of death, and may later share the regret of this writer.

> I will never forget my uncle complaining bitterly two days before he died about his family treating him like a helpless child and insisting he would recover whenever he started to talk about dying or his fear of never leaving the hospital. I was only fourteen and did not fully understand what he was trying to tell me at the time but I never forgot his pain or anger as he tried to explain the feeling of dying without emotional support. (Galvin and Brommel, 1982, p. 237)

The avoidance of truth can be contagious, and in its way is a painful and debilitating part of terminal illness. One husband, with the cooperation of the attending physician, insisted that his wife be told she had a curable ulcer instead of terminal cancer. His wife knew the truth, as most dying patients do, but was cheated of the chance to say the things which heal the spirit. She left her family a note which began:

> There has been so much that I have wanted to tell you over the past nine months. I didn't because I couldn't bear to, and I was afraid to question too much because I must have known the answer all the time--and maybe because I thought

you couldn't bear to listen. Probably both. Now there's no time left . . . . (Kliman, 1978, p. 40)

In contrast to this destructive reticence, hospice care is based on honesty. Euphemisms are avoided, the journey is acknowledged as shortening but still important, staff and volunteers are willing to talk about death, families are expected to be honest, and every patient is told the truth. Such honesty has the effect of creating choices. A patient who has all the facts is freed to make decisions and reassert control over his/her own life journey.

Although honesty about death is essential to the hospice concept, such openness confronts long-standing cultural and medical constraints. The personnel who serve the patient and family can in turn be served by the body of communication research and insight which supports the hospice commitment to honesty.

Laing (1969), for example, offers an analysis of double bind situations in which contradictory messages are conveyed and any response of the listener will be partially wrong (pp. 125-131). Families who offer a patient unusually solicitous attention but refuse to acknowledge the reason can place the patient in such a double bind. Some families may acknowledge the impending death verbally, but nonverbally express a constant demand for the patient to survive. Laing's analysis of the destructive effects of double bind communication helps justify the constant honesty which the hospice staff gently brings to patient and family. The ability to apply Laing's insights can help hospice personnel to intervene in ways that will lessen psychological pain.

Other information which a communication scholar might offer includes Jourard's (1971) ideas on self-disclosure, particularly his references to personalized nursing care (pp. 200-207); Galvin and Brommel's (1982) analysis of the role of communication in family crises, including their emphasis that honest expression is essential to allow healthy preparatory grief (pp. 236-239); and Arnold's (1980) perspective on crisis communication, which includes awareness of the nonverbal signals which are often more truthful than words (p. 41).

When faced with emotional or psychological pain, "the truth shall set us free." The hospice concept is committed to this premise and conclusions drawn from communication studies can support and sustain this essential precept.

Communication Which Retains Reciprocity

As the treatment goals for a dying person move from cure to comfort, the interaction with that person should move from therapeutic to relational communication. Although some mutuality of concern, influence and self-disclosure is desirable even in a diagnostic, curative relationship--such reciprocity is central to the hospice concept of care. Without reciprocity, care degenerates into charity or custodial maintenance--both of which are degrading to the recipient and alien to hospice philosophy.

Every person, regardless of age or state of health, has something to offer, needs to make a difference, needs to give as well as receive. Hospice personnel must be willing to receive what the dying person wants to give, lest their care be diminished by condescension. In her novel Final Payments, Mary Gordon portrays the anguish of those who are trapped

by dehumanizing charity and particularly criticizes the do-gooder who gives freely, unfeelingly, without ever receiving. She writes (1978): "I know of nothing that moved John Ryan, neither pain nor grace, and I thought it miserably unfair that his actions should have such a profound effect on people whose lives had no effect on his" (p. 69). The hospice concept rejects such impersonal charity and also rejects the custodial mentality that addresses a person's symptoms without appreciation of the person's spirit. Hospice offers an alternative to the institutional approach described by this doctor: "The profession of medicine appears to ignore the human spirit. When I see patients in nursing homes who have become only bodies, I wonder whether it is not their transcendent dimension that they have lost" (Cassell, 1982, p. 643).

In a reciprocal relationship, the complexity of each person is respected. Within the hospice context, the patient is more than a body and the helper is more than a starched caretaker. Each is free to transcend his role. The best hospice volunteer has moments of uncertainty and depression; and, given the opportunity, the patient is often the best comforter. The dying person, when freed from physical pain (the first step in all hospice care), still possesses wit, talents, and wisdom--qualities which may be deepened by personal crisis. Each has a story to tell about his/her particular journey; that story reveals complexities of human response that illustrate, surpass, and sometimes contradict the anticipation of death as described by Kübler-Ross (1970, p. 36); some patients may not reach Kübler-Ross's description of acceptance but may be eloquent in their anger or extraordinary in their resistance. That hospice personnel have

much to learn from each patient is emphasized by Dr. Margaret Scott, director of the palliative care unit of Toronto's Grace Hospital:

> You have to have the ability to receive from the dying. We see courage, fear, unfulfilled dreams; we see dreams being realized; we see problems being resolved or consciously shelved; we see the way people face basic issues as well as trivial issues. Almost all of these patients and their families have shared with us their sorrow, their worry, their joy, and from that we are learning how to help others. (Gerard, 1980, p. 68)

The communication specialist can support this recognition of mutuality by offering insights from Rogers' (1961) perspective on helping relationships (pp. 39-58), Stewart's (1982) analysis of the meeting of persons, Halmos' (1970) recognition that successful counseling involves some mutual assimilation of personal qualities (pp. 99-105), and Mayeroff's (1971) views on the reciprocity of caring (pp. 36-38). These and other theorists confirm the mutuality that successful hospice helpers have intuitively practiced.

Conclusion

As a hospice team member or consultant, the communication scholar is not offering esoteric knowledge, but is returning to professional and volunteer helpers some systematic observations and tested insights that they themselves have proven to be true. Thus, the efforts of a caring team can be strengthened through self-understanding and objective confirmation.

Consider again Dante's words: "In the middle of the journey of our life I came to myself in a dark wood where the straight way was lost."

But consider also these lines from George Eliot: "The years seem to rush by now, and I think of death as a fast approaching end of a journey--double and treble reason for loving as well as working while it is day."

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